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ABSTRACT

This testimony before the U.S. Senate Committee on the Budget discussed Medicaid coverage of children with disabilities and the proposed Family Opportunity Act of 2000 that would create a new state option to allow parents who have a child with a severe disability or a potentially severe disability to purchase health care coverage for the child through the Medicaid program. The testimony discussed the role Medicaid plays currently in providing health care coverage for children with disabilities, the extent to which private insurance offers coverage of needed services for children with disabilities, and the benefits and services available to children under the Medicaid program. It found that despite the extent of Medicaid's coverage in providing insurance to children receiving Supplemental Security Income (SSI), over 120,000 children who met the requirements for disability in 1999 were initially denied eligibility when they applied or later had their benefits suspended because their family's income or resources had exceeded SSI limits. The testimony concluded that for families with a child with severe disabilities, particularly those with incomes and resources that are just above Medicaid thresholds, the ability to purchase Medicaid coverage could be an important means of obtaining health care for their children. (CR)

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CHILDREN WITH DISABILITIES

Medicaid Can Offer Important Benefits and Services

Statement of William J. Scanlon, Director
Health Financing and Public Health Issues
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Children With Disabilities: Medicaid Can Offer Important Benefits and Services

Mr. Chairman and Members of the Committee:

We are pleased to be here today as you explore the possibility of allowing some families with children with disabilities the opportunity to purchase Medicaid coverage. Almost 1 million children with disabilities receive Medicaid coverage because of their eligibility for the Supplemental Security Income (SSI) program. Additional children with disabilities also qualify for Medicaid under other criteria, such as medically needy programs for persons with high medical expenses or the Katie Beckett option, which allows coverage of children who would be Medicaid eligible if they resided in an institution.

Concerns have been raised that some children lose Medicaid coverage when family incomes increase and they cease to be SSI or Medicaid eligible. Other children with disabilities reside in families with incomes that exceed SSI and Medicaid requirements and may have limited access to other sources of health insurance. For children with special health care needs, access to health insurance is particularly important to assure access to services. Children with special health needs are three times as likely to be ill, almost three times as likely to miss school due to illness, and use over five times as many annual hospital days as other children. They are also twice as likely to have unmet health needs as children in the general population. Without access to proper preventive health care and treatment services, these children are at risk for greater incidence of complicating illnesses and hospitalization.

The proposed Family Opportunity Act of 2000 (S. 2274) would create a new state option to allow parents who have a child with a severe disability or a potentially severe disability to purchase health care coverage for the child through the Medicaid program. Today, my remarks will focus on (1) what role Medicaid plays currently in providing health care coverage for children with disabilities, (2) the extent to which private insurance offers coverage of needed services for children with disabilities, and (3) the benefits and services available to children under the Medicaid program. My comments are based on our prior work in Medicaid, SSI and private insurance; a list of related reports follows the text of my comments.

In summary, Medicaid generally covers children with disabilities who receive SSI benefits. In December 1999, almost 850,000 children were receiving SSI payments. These children represent 18 percent of the 4.7 million children with chronic physical or mental conditions of which children with severe disabilities are a subset. Despite the extent of Medicaid's coverage,

-In 1999, over 120,000 children who met the requirements for disability, were initially denied eligibility when they applied or later had their benefits suspended because their family's income or resources had exceeded SSI limits.

-SSI eligibility rules can create a bias towards institutional care for children with disabilities because the income and resources of parents of a child with disabilities are excluded in determining eligibility once a child has been in an institution for more than 30 days.

-Limited mental health coverage in parents' private insurance plans can create an incentive to use a foster care arrangements as a means of obtaining or maintaining access to Medicaid eligibility and services. In many cases, children with psychiatric needs—the basis of eligibility for over 27 percent of children in 1999–have access to private health insurance but this insurance may have limited mental health coverage. By becoming wards of states' child welfare systems, they can obtain or continue their Medicaid eligibility.

Several options exist for states to expand coverage for children with disabilities or special health care needs in Medicaid besides the link to SSI eligibility. In particular, "spend down" options can result in children being sporadically eligible for Medicaid, and states' expansions of eligibility for certain categories of children with disabilities may not be available to all children, even if they meet the eligibility and income requirements.

Private health insurance is often not available and can be a more limited option for many children with disabilities. In particular, families with children with special health care needs whose income rises above the maximum threshold allowed for SSI and Medicaid often have limited options for obtaining private health insurance that will cover the services the children need. Many of those leaving SSI and Medicaid work in lower-wage jobs that often do not have access to group coverage or may find their share of premium costs unaffordable. While the Health Insurance Portability and Accountability Act of 1996 (HIPAA) guarantees that certain children have access to individually-purchased health insurance without exclusions for pre-existing conditions, this coverage is also likely to be unaffordable for many. For those individuals who do obtain private health insurance coverage, the benefits provided may be limited so that some services that are important for children with disabilities are not covered.

While private insurance generally covers acute health care services for children, Medicaid usually offers a more comprehensive package of benefits that includes the use of services designed for chronic and long term care needs. Medicaid managed care programs, which a number of

states have or are implementing for children with special needs, may have the capability to more comprehensively address their extensive and complex needs than private health insurance plans that serve few persons with such needs. In particular, managed care plans may link beneficiaries to a regular case manager and a care provider, thereby improving coordination and continuity of care.

Background

Although there is no consensus definition, children with special health care needs often have a serious physical or mental disability (such as cerebral palsy or mental retardation), a chronic medical condition (such as diabetes or asthma), a requirement for significant amounts of medical care or services (such as around-the-clock nursing care), or a combination of impairments. For example, a child with autism can experience developmental delays and behavior problems, and a child with cerebral palsy may also have quadriplegia. Researchers estimate that there are approximately 4.7 million children with special health care needs who experience limitations in activities such as school or play because of chronic physical or mental conditions.

The Congress established the SSI program, which is administered by the Social Security Administration (SSA), in 1972 to provide cash payments to aged individuals and blind and disabled adults and children with limited income and resources. Children may qualify for SSI if they meet the applicable SSI disability, income, and financial asset requirements. To be eligible, a child must be younger than 18 and must have a medically determinable physical or mental impairment that results in marked and severe functional limitations. These impairments (1) can be expected to result in death or (2) have lasted or can be expected to last for a continuous period of not less than 12 months. A segment of the 4.7 million children with an activity limitation have disabilities severe enough to meet their standard.

In addition, the child's family must have limited income and assets.[1] A child's family meets the SSI income requirements if his or her parent's countable income is below the maximum SSI limits (see table 1). Once a child is on the SSI rolls, eligibility continues until (1) death, (2) the family's economic resources no longer meet SSI's eligibility requirements, (3) SSA determines that the child's medical condition has improved to the point that he or she is no longer considered disabled, or (4) SSA determines that

[1]The definition of childhood disability is found in 42 U.S.C. 1382c(a)(3)(C)(i). SSA considers the parent's income and assets when deciding whether a child qualifies for SSI.

the child, upon reaching age 18, is not disabled according to adult disability criteria.

Table 1: Countable Income and Resources, and Principal Income Exclusions for SSI

Requirement	Countable income or resources (after exclusions)	Principal exclusions to countable income or resources
Income[a]	Below $512 a month for one-parent family (excludes allowances for parent and other children) Below $769 per month for a two-parent family (excludes allowances for parent and other children)	$20 per month of most income $65 per month of wages and one-half of wages over $65 food stamps home energy/housing assistance
Resources (property and other assets a person owns)	$2,000 for a one-parent family $3,000 for a two-parent family	the home a person lives in a car, depending on need burial plots and funds up to $1,500 for funeral expenses life insurance with face value of $1,500 total for family member(s)

[a]Most states offer supplement[s] to SSI and a person's income can be higher and still qualify. State SSI supplemental recipients are usually eligible for Medicaid.

Source: SSA A Desktop Guide to SSI Eligibility Requirements (Baltimore, MD.: Social Security Administration, January 2000) http://www.ssa.gov/pubs (cited July 6, 2000).

The Medicaid program, a federal-state entitlement program that finances health care for certain low-income individuals, also provides assistance to children with disabilities.[2] The federal government pays a proportion of a state's Medicaid expenditures that ranges from 50 to 83 percent depending on each state's per capita income. In 1998, Medicaid spent about $177 billion to provide health insurance coverage to over 40 million Americans, over half of whom were children.

Most states' Medicaid programs offer a wide array of therapies and services that are important for children with special health care needs. Physical, occupational, and speech therapies, as well as rehabilitative and case management services, are all common benefits offered to most

[2]In addition to Medicaid and SSI, other federal programs provide services to children with disabilities, including the Special Education and Early Intervention under the Individuals With Disabilities Education Act (IDEA); and the Children With Special Health Care Needs program under title V of the Social Security Act. For more information on these programs, see *Medicaid Managed Care: Challenges in Implementing Safeguards for Children With Special Needs* (GAO/HEHS-00-37, Mar. 3, 2000) and *SSI Children: Multiple Factors Affect Families' Costs for Disability-Related Services* (GAO/HEHS-99-99, June 28, 1999).

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Medicaid eligible individuals. While limitations may be imposed on the receipt of such services, Medicaid provides children a special entitlement to health care through the provision of Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services. Established in 1967, the central principles behind EPSDT are those of prevention–to locate low-income children, assess their health status at key points, and provide care to identify, control, or correct physical and mental health problems. Among other requirements, EPSDT mandates that states cover any service or item that is medically necessary to correct or ameliorate a child's condition, regardless of whether the service or item is otherwise covered under a state Medicaid program.[3]

The Family Opportunity Act of 2000, S. 2274 introduced by Senators Grassley, Jeffords, Kennedy, Harkin, Reed, and Moynihan would allow states to permit families with children that meet the SSI definition of disability but whose income exceeds a state's Medicaid eligibility standard to "buy-in" to Medicaid. Families would pay a state-established premium that could be up to the full cost for the Medicaid buy-in. Premiums could not exceed 5 percent of income for those at or below 300 percent of poverty and 7.5 percent of income for those between 300 and 600 percent of poverty. The bill would also

- allow states to include children receiving hospital psychiatric services in the state's home- and community-based services (HCBS) waiver programs,[4]
- establish a demonstration program to extend Medicaid to children with a disability that is not yet severe enough to meet SSI's definition but would be expected to become so without health care, and
- establish family-to-family health information centers to provide technical assistance and information to families about health care programs and services available for children with special health needs.

[3]The statutory requirements of EPSDT are in 42 U.S.C. Section 1396d(r).

[4]Under Section 1915(c) of the Social Security Act, the Secretary of Health and Human Services may waive certain provisions of the Medicaid statute to provide home and community based services.

Children With Disabilities Most Frequently Qualify for Medicaid Because of Eligibility for SSI

Most children counted by Medicaid as disabled—approximately 1 million in 1997—qualify for Medicaid coverage because they are receiving SSI benefits.[5] States may link eligibility for Medicaid with SSI in one of three ways. First, the law allows automatic Medicaid eligibility when a person becomes entitled to SSI. Thirty-two states and the District of Columbia have elected this option. Second, in 7 states, SSI recipients are eligible for Medicaid, but they must file a separate application with the state agency that administers Medicaid. Third, the remaining 11 states do not use SSI eligibility, but have chosen their own Medicaid eligibility criteria for individuals with disabilities.[6]

In December 1999, the SSI program covered close to 850,000 children with disabilities, a number that represents 18 percent of the over 4.7 million children estimated to have special health care needs and experience limitations in activities such as school or play because of chronic physical or mental conditions. Only some of these 4.7 million children have limitations or disabilities severe enough to meet SSI's definition of disability. Thus, SSI may cover more than 18 percent of children with severe disabilities,[7] but the proportion it actually covers is not currently known.

Retaining Medicaid Eligibility Through SSI Can Be Problematic

Many children with disabilities are ineligible—or lose SSI eligibility—because of family income. In 1999, 14,900 children with disabilities applied for SSI and were deemed disabled; however, they did not receive benefits because their families' income or resources were too great. Of these 14,900 children, 72 percent were denied because their families had excess income, while 28 percent had excess resources. During the same year, 113,400 children who had been receiving SSI were suspended from the program because their families' income or other resources grew to exceed

[5]Many eligibility categories for Medicaid do not identify whether individuals have disabilities; thus other children with disabilities receiving Medicaid may not be included in this count of 1 million.

[6]Under Section 1902(f) of the Social Security Act, states are allowed to use their 1972 assistance eligibility rules in determining Medicaid eligibility for individuals with disabilities, rather than SSI eligibility. The 11 states that have chosen this option are known as "section 209(b)" states, after the Section of the Social Security Amendments of 1972 that established it. SSI recipients not eligible for Medicaid in Section 209(b) states must be allowed to "spend down" and become eligible after their income is lowered to the Medicaid eligibility level.

[7]Nearly 70 percent of children receiving SSI lived in households where the average monthly income was less than $1,000. The most common type of unearned income was public income-maintenance payments, which includes Temporary Assistance for Needy Families (TANF), Department of Veterans Affairs payments based on need, and other governmental programs. No income information is available for the 114,970 children with no parents. Appendix I has selected characteristics of children receiving SSI.

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program limits.[8] Most of those children, 94 percent, had family incomes that were too high, while 6 percent were in families with excess resources. Some of these children may still qualify for Medicaid because of federal or state eligibility expansions discussed below.

SSI eligibility rules can create a bias towards institutional care for children with disabilities as a means of obtaining Medicaid coverage. SSI eligibility rules do not count the income and resources of parents of a child with disabilities once the child has been in an institution for 30 days. Parents who are not poor, but who cannot afford to meet the financial and medical needs of a child with disabilities, may place the child in an institution to be eligible for Medicaid coverage. Approximately 8,200 children with disabilities receiving SSI (less than 1 percent) resided in institutions during the period October 1997 to September 1998.

Limited mental health coverage in parents' insurance plans can result in some children being placed in foster care arrangements as a means of obtaining or maintaining access to Medicaid eligibility and services.[9] Among the children that qualified for SSI, over 27 percent were identified as having psychiatric disorders. A recent study reported that in 27 states, custody relinquishment has occurred as a means of ensuring that children receive Medicaid mental health services.[10] In many cases, these children have access to health insurance, but have limited mental health coverage in private insurance plans; however, by becoming wards of states' child welfare systems, they can obtain or continue their Medicaid eligibility.

[8]SSI cash benefits stop upon suspension; however, a child can reapply at any time if family income or resources again decrease below the SSI requirements. For data on SSI suspensions, see *SSI Annual Statistical Report 1999* (Baltimore, MD: Office of Research, Evaluation, & Statistics, June 2000), pp. 57-58.

[9]Children in federally funded foster care or children with special needs in federally funded adoption assistance programs are eligible for Medicaid. Additionally, children in state funded foster care or adoption assistance programs can, at the state's option, also be eligible for Medicaid benefits.

[10] See *Relinquishing Custody: The Tragic Result of Failure to Meet Children's Mental Health Needs* Bazelon Center for Mental Health Law, Washington, DC: March 2000.

Other Avenues to Medicaid Eligibility for Children With Special Health Care Needs Can Also Be Problematic

While Medicaid eligibility expansions have increased the potential for children living in poverty or near poverty to receive Medicaid benefits, problems remain, particularly for children in families with incomes slightly higher than those allowed by Medicaid. In addition to federal mandates expanding Medicaid eligibility for children,[11] many states have implemented optional medically needy and home and community based services programs that also expand eligibility and are important to children with special health care needs. While significant, these expansions can result in episodic Medicaid coverage or have limited availability for children with special health care needs.

Medically Needy Eligibility Can Result in Episodic Coverage

Under the medically needy option, states can extend Medicaid coverage to children who are disabled but would not qualify because their family's countable incomes are too high. However, when medical expenses are deducted from their incomes, the remainder falls below state established thresholds for being medically needy.[12] As of 1998, 35 states and the District of Columbia had elected to offer coverage to medically needy individuals. While providing care during times of financial stress, families with incomes just over the Medicaid income requirements can bounce in and out of Medicaid eligibility, depending on the medical needs of the child. Episodic conditions—such as acute asthma—can be especially problematic as expenses can vary greatly, thus affecting a child's eligibility for Medicaid.

Home and Community Based Services (HCBS) Waivers Have Limits on Eligibility and Services

Under Section 1915(c) of the Social Security Act, the Secretary of Health and Human Services may waive certain provisions of the Medicaid statute to provide home and community based services. Children receiving Medicaid coverage under an HCBS waiver must, absent home and community based services, require the level of care furnished in a hospital, a nursing facility, or an intermediate care facility for individuals with mental retardation. Income and resource eligibility criteria can, at the states' option, be higher for HCBS services. As of June 2000, at least 31 states operate 49 HCBS waiver programs that provide services to children with disabilities, most commonly serving children with developmental

[11] Federal law mandates that all children born after September 30, 1983, in families up to 100 percent of the federal poverty level are eligible for Medicaid. Additionally, infants and children up to age six are eligible if residing in families up to 133 percent of the federal poverty level.

[12] Under this option, a state establishes an income and resource standard and deducts the medical expenses an individual has incurred over a budget period (not more than 6 months) from the individual's countable income. If the recalculated income is less than the state's medically needy income standard—and if countable resources are within the state's medically needy resource standard—then the child is eligible for Medicaid for the remainder of the budget period. At the end of the budget period, the individual's medically needy status must be redetermined for a new budget period.

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disabilities. While HCBS waivers allow states more flexibility in program design, they can also limit states' expenditures by targeting services to specific populations, geographic areas, or both. In addition, they may have a cap on the number that can be served. As a result, not all children may be able to access waiver services.

Most States Do Not Use the Katie Beckett Option to Expand Eligibility for Children With Disabilities

The Katie Beckett option allows states to offer Medicaid eligibility for children who live at home and (1) meet the SSI standard for disability and (2) need a level of care provided by an institution. As of 1996, 20 states and the District of Columbia used this eligibility category. For the remaining states that have not employed this option, parents with incomes higher than the Medicaid threshold that have children with disabilities could face the choice of placing their child in an institution as a means of obtaining Medicaid coverage.

Private Health Insurance is Often Not Available and Can Be a More Limited Alternative for Many Children With Disabilities

Private health insurance is often not available and can be a more limited option for many children with disabilities. Families with children with special health care needs whose incomes rise above the maximum allowed for Medicaid have limited options for obtaining other health coverage that will cover necessary services. Many families with children with disabilities who are eligible (or near eligible) for Medicaid work in lower-wage jobs that may not provide access to group health insurance or may require premiums and cost-sharing that families find unaffordable. Federal and state laws guarantee that certain individuals losing group coverage, including children with special health care needs who lose Medicaid, can access individually-purchased private health insurance, but this insurance may be prohibitively expensive for many families. Moreover, even those who can obtain private health insurance may find that the coverage for some services relied on by children with disabilities are more limited than under Medicaid.

Group Health Coverage Is Unavailable to Many Low-Income Families

Data on the health insurance status of children with disabilities indicates that group health insurance has been unavailable or unaffordable to many low-income families. In 1994 and 1995, children with a disability in families with incomes below the federal poverty level relied predominantly on Medicaid and other public programs for coverage, whereas only half of children with disabilities in families with incomes between 100 and 200 percent of the federal poverty level had private health insurance. Almost a fifth of these children were uninsured. (See table 2.) The State Children's Health Insurance Program (SCHIP) enacted as part of the Balanced Budget Act of 1997 may be providing some of these uninsured children

with coverage. Data on how much of a difference SCHIP has made for children with disabilities are not available.

Table 2: Health Insurance Status of Children With Disabilities, 1994-1995[a]

	Population (thousands)	Private coverage only (percent)	Public coverage only[b] (percent)	Private and public coverage (percent)	Uninsured (percent)
Less than 100% of federal poverty level	2,984	10.2	68.5	4.5	16.7
100% to 199% of federal poverty level	2,946	49.7	28.3	3.9	18.1
200% or more of federal poverty level	5,329	87.6	5.8	2.6	4.1
Total	12,455[c]	56.2	29.1	3.5	11.2

[a]Data on health insurance status did not stratify children by severity of disability.

[b]Includes Medicaid, Medicare, military, Civilian Health and Medical Program of the Uniformed Services, and other public assistance programs.

[c]Columns do not add to total because the total includes children in families with unknown income.

Source: Based on an analysis of the 1994-1995 National Health Interview Survey on Disability. See Paul W. Newacheck et al, "Access to Health Care for Children with Special Health Care Needs," Pediatrics, Vol. 105, No. 4 (April 2000), pp. 760 to 766.

Many families with children with disabilities whose incomes are–or rise to–a level above states' Medicaid income eligibility thresholds have low-wage jobs that often do not offer health insurance benefits. Only 55 percent of low-wage employees paid $7 per hour or less have access to employer-sponsored health coverage compared to 96 percent of employees paid $15 per hour or more. Further, even those low-wage employees who are offered health insurance may not elect to accept the coverage. Nearly one-fourth (24 percent) of low-wage workers who were offered health insurance by their employer declined coverage, primarily due to the cost of having to pay a share of the premiums.[13]

[13]Philip F. Cooper and Barbara Steinberg Schone, "More Offers, Fewer Takers for Employment-Based Health Insurance: 1987 and 1996," *Health Affairs*, Vol. 16, No. 6 (1997), pp. 142 to 149.

Individually-Purchased Insurance Can Be an Expensive Alternative

For those families of children with disabilities who lose Medicaid coverage but are not eligible for group health coverage offered by an employer, the individual insurance market may offer a very expensive alternative. HIPAA guarantees that individuals losing Medicaid after at least 18 months of continuous coverage must be offered individually purchased health insurance without exclusions for preexisting conditions.[14] However, HIPAA does not address the affordability of coverage, and carriers in the individual insurance market typically deny coverage or charge higher premiums for individuals with medical conditions, known as medical underwriting. As a result, the premiums may be prohibitively expensive.

For example, in a prior review of children's health insurance products, we found that some carriers deny coverage for children with conditions such as autism, cerebral palsy, Downs syndrome, emotional disorders, and epilepsy.[15] If required by HIPAA to offer coverage to children with these conditions and prior Medicaid coverage, the carrier would likely charge the highest premium allowed by state regulations. For example, in 14 states using the federal rather than state rules guaranteeing access, we found that HIPAA-eligible individuals with severe diabetes as a preexisting condition are typically charged at least 300 percent of standard premiums charged healthy individuals, and as much as 464 percent more.[16] Children with chronic disabilities may have even greater health care needs and could therefore face premiums that are at least as high as those charged to adults with diabetes.

More than half of the states have high-risk pools that provide private health insurance coverage to individuals who are denied individual health insurance coverage and (in 22 states) HIPAA-eligible individuals. However, nationwide these pools served fewer than 100,000 people in 1997 and some have waiting lists for non-HIPAA eligible participants that exceed their limits on enrollment. A family of a child with disabilities participating in a high-risk pool would pay for this coverage, but states typically cap the cost at 150 percent or less of the standard insurance rate for a healthy individual.

[14]To be eligible for guaranteed individual insurance coverage through HIPAA, the individual must have 18 months of continuous prior coverage through Medicaid or other group health plans, a gap in coverage not exceeding 63 days, and not be eligible for other group health coverage.

[15]*Health Insurance for Children: Private Individual Coverage Available, but Choices Can Be Limited and Costs Vary* (GAO/HEHS-98-201, Aug.5, 1998).

[16] *Private Health Insurance: Progress and Challenges in Implementing 1996 Federal Standards* (GAO/HEHS-99-100, May 12, 1999).

Private Coverage for Services Important to Children With Disabilities Is Frequently Limited

For those individuals who do obtain private health insurance coverage–whether through a group plan, individually purchased plan, or a high-risk pool–the benefits provided might be limited in some areas that are important for children with disabilities. While private health insurance plans typically cover some services important to children with disabilities, such as physical, occupational, and speech therapy; mental health; and home health care, these benefits are typically limited and require the patient to share the costs of services through a deductible, copayment, or coinsurance. For example, typical mental health coverage in an employer-sponsored group health plan limits mental health services to 30 hospital days and 20-outpatient office visit per year and requires the patient to pay 50 percent coinsurance. Further, the benefits for these services are typically intended for short-term rather than chronic care. For example, private health plans may only cover care for a short-term period, such as 30 rehabilitative visits within a 60-day period, and require that significant improvement in the condition be expected. Similarly, health plans typically make coverage conditional on a determination of medical necessity, and this may depend on an expectation of improved medical condition. In contrast, many children with disabilities may require health services to maintain a given level of ability rather than expecting improvement.

Medicaid Can Offer a Comprehensive Benefits Package for Children With Disabilities

While private insurance generally covers acute health care services for children, Medicaid can offer a more comprehensive package of benefits that includes the use of services designed for chronic and long term care needs. For example, most states offer case management services, which are designed to assist beneficiaries in getting medical, social, educational, and other services. Medicaid also offers personal care services, which provides assistance with basic daily activities such as bathing and dressing, and intermediate care facilities for individuals with mental retardation/developmental disabilities. HCBS waivers further expand Medicaid's benefit package to include services such as respite care, which provides relief to the primary caregiver of a chronically ill or disabled beneficiary.

In contrast to the limits private health plans typically place on many services valued by children with special health care needs, Medicaid provides comprehensive services with no or nominal cost sharing by participants. Moreover, to the extent that states have limitations on benefits and services under their Medicaid programs, EPSDT provides an avenue for ensuring that children receive any medically necessary

service.[17] While evidence exists that certain elements of EPSDT are poorly implemented, [18] the legislation establishing EPSDT does provide an avenue for providing coverage to children with disabilities for necessary health screens and services. Moreover, the standard of care for EPSDT includes relief of pain and maintenance of a level of health—a contrast to private insurance policies, which can be structured to deny care if improvement in conditions do not occur.

Medicaid may also have the capability to more comprehensively address the care needs of these children than private health plans. Individual private plans may include very few children with severe disabilities and thus developing special programs and arrangements for them may not be economically justified. Medicaid programs, as the major insurer of these children, may find it advantageous to design specially tailored programs that both better serve the children and are more efficient. In particular, since the mid-1990s, states have been increasing enrollment of children with disabilities in capitated Medicaid managed care programs. While some concerns exist about the appropriateness of capitated managed care for these children, well designed and well implemented managed care programs may have the potential of better serving these children. Employing sufficient safeguards to assure adequate and appropriate services can ameliorate these concerns.[19] Managed care can potentially provide benefits for children with disabilities, including linking beneficiaries to a case manager and a regular care provider and thus improving coordination and continuity of care.

Concluding Observations

For families with a child with severe disabilities, particularly those with incomes and resources that are just above Medicaid thresholds, the ability to purchase Medicaid coverage could be an important means of obtaining health care for their children. Precisely because it is the single largest source of health care financing—public or private—for low-income individuals with disabilities, Medicaid offers a unique set of benefits and capabilities. While problems in Medicaid certainly exist – for example,

[17] Social Security Act § 1905(r), 42 U.S.C. §1396d(r).

[18] See *Lead Poisoning: Federal Health Care Programs Are Not Effectively Reaching At-Risk Children*, (GAO/HEHS-99-18, Jan.15, 1999) and *Medicaid: Elevated Blood Lead Levels in Children* (GAO/HEHS-98-78, Feb. 20, 1998).

[19] The Health Care Financing Administration (HCFA) has published interim safeguard requirements for states mandating enrollment of children with special needs into capitated managed care. HCFA plans to revise these requirements after conducting studies regarding appropriate safeguards for children with special needs in managed care. See *Medicaid Managed Care: Challenges in Implementing Safeguards for Children With Special Needs*, (GAO/HEHS-00-37, Mar. 3, 2000).

complex eligibility rules and variation across states – it nevertheless can provide the basis for comprehensive coverage and case management for children with disabilities.

Mr. Chairman, this concludes my prepared statement. We would be happy to answer any questions that you or Members of the Committee may have.

GAO Contacts and Staff Acknowledgments

For more information regarding this testimony, please contact William J. Scanlon at (202) 512-7114 or Carolyn Yocom at (202) 512-4931. John Dicken and Karen Doran also made key contributions to this statement.

Selected Demographic and Diagnostic Characteristics of Children Receiving SSI, December 1999

Table 3: Selected Demographic Characteristics of the 843,470 Children Receiving SSI, December 1999

Characteristic	Number of children	Percentage
Monthly household income not including SSI[a]		
None	223,720	30.7
Under $200	119,040	16.3
$200-399	33,790	4.6
$400-599	41,480	5.7
$600-999	83,310	11.4
$1000 or more	227,160	31.2
Age		
0-5	166,750	19.8
6-9	206,780	24.5
10-13	241,400	28.6
14-17	228,540	27.1
Sex		
Female	306,890	36.4
Male	536,580	63.6

[a]Includes monthly income of households headed by single adults and couples. No parental income information exists for the 114,970 children with no parents.

Source: SSA, Children Receiving SSI (Baltimore, MD.: Office of Research, Evaluation, and Statistics, Dec. 1999), http://www.ssa.gov/statistics/children_receiving_ssi/121999/chreport.pdf (cited July 6, 2000). SSA projected these numbers from a 10 percent sample of children receiving SSI benefits drawn from its supplemental security record file, Dec. 1999.

Table 4: Selected Conditions of Children Receiving SSI, December 1999

Diagnostic Group[a]	Number of children	Percentage
Mental impairments		
Mental retardation	291,770	36.9
Other psychiatric	213,060	27.0
Schizophrenia	4,150	0.5
Physical impairments		
Diseases of the nervous system and sense organs	96,750	12.3
Congenital anomalies	41,900	5.3
Diseases of the respiratory system	25,060	3.2
Neoplasms	9,520	1.2
Diseases of the musculoskeletal system and connective tissues	7,680	1.0
Endocrine, nutritional, and metabolic	6,360	0.8
Injury and poisoning	4,360	0.6
Diseases of the circulatory system	4,070	0.5
Infectious and parasitic diseases	3,010	0.4
Diseases of the digestive system	2,990	0.4
Diseases of the genito-urinary system	2,320	0.3
Other[b]	76,790	9.7
Total	789,790	100.0

[a]Numbers are based on the children for whom a diagnostic code is available in SSA's Supplemental Security Record file.

[b]Includes conditions for which a diagnosis has been established but is not included in SSA's medical listing of impairments.

Source: SSA, Children Receiving SSI (Baltimore, MD.: Office of Research, Evaluation, and Statistics, Dec. 1999), http://www.ssa.gov/statistics/children_receiving_ssi/121999/chreport.pdf (cited July 6, 2000). SSA projected these numbers from a 10 percent sample of children receiving SSI benefits drawn from its supplemental security record file, Dec. 1999.

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Medicaid and Special Education: Coordination of Services for Children With Disabilities Is Evolving (GAO/HEHS-00-20, Dec. 10, 1999).

SSI Children: Multiple Factors Affect Families' Costs for Disability-Related Services (GAO/HEHS-99-99, June 28, 1999).

Private Health Insurance: Progress and Challenges in Implementing 1996 Federal Standards (GAO/HEHS-99-100, May 12, 1999).

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Health Insurance for Children: Private Individual Coverage Available, but Choices Can be Limited and Costs Vary (GAO/HEHS-98-201, Aug. 5, 1998).

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